

Testimony of Stanley Peters to the Committee on Public Health about Raised S.B. No. 294
AN ACT CONCERNING SERVICES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY
March 1, 2016

My name is Stanley Peters and I live with my wife Kathleen Peters in Killingworth, Ct. We are the parents of a 32 year old daughter with Intellectual and Developmental Disabilities (IDD). We would like to thank Senator Gerratana and Representative Ritter and members of the Public Health Committee for Raising SB 294. It is important that a bill such as this one be passed so that citizens with IDD (our children) and their families are assured basic rights when dealing with the Department of Developmental Services (DDS). This bill is a start. However I believe there are several key issues that are either not addressed or inadequately addressed.

First, in section 1 (3), the wording seems to limit the waiting list definition to those in “urgent” need of services. In our dealings with DDS urgent has not been a term that they have used. DDS uses the terms Emergency, Priority 1, Priority 2, and Priority 3. Since the bill does not define “urgent” I believe that DDS would interrupt urgent as emergency and that will put us in the same place as we are in now with just a very few receiving any new services. Please consider changing the wording to include all on the residential waiting list.

Second, the bill does not make clear how often a recipient and their family are to be notified of their status within the DDS system. Please consider adding wording that notification of status should be at a minimum yearly or whenever a change occurs.

Third, it is absolutely critical that the bill be amended so that any individual requesting services or an increase in supports from DDS be provided with copies of the documents that were used by DDS to form the basis for their decision. Generally, a request for services or an increase in supports comes out of a meeting with the DDS case manager. The case manager takes the meeting notes and writes the request and submits it to the regional Planning and Resource Allocation Team (PRAT) who decides if the person will receive the requested services or supports. From our own personal experience, learning after the fact, we can tell you that what was said at a meeting and what was written up and submitted to PRAT were two different things. The bill should require that the request to PRAT be approved by the individual/parent/guardian etc. prior to being submitted to PRAT. It should also require that PRAT provide a written explanation detailing how they arrived at the decision to grant or deny the request. A detailed explanation is critical in cases where the parent/guardian wishes to challenge the decision and requests a higher level review. If you disagree with a PRAT decision you can request a Programmatic Administrative Review (PAR) with your regional director for DDS. And if you disagree with that decision you can request a Commissioner’s Review/Programmatic Administrative Review. We did both for our daughter. In the first one with the regional director we tried to make our case as best we could at the time without having any of the information that was submitted to PRAT and not having any information on why PRAT denied the request. It was at this PAR meeting that we were given the information we had requested as the regional director was telling us that he was denying our request. While the information on the request that the case manager had submitted to PRAT was clear (poorly written and misleading, but clear), the PRAT rejection was a check box form and it was totally unclear why they had rejected the request or what their reasoning was for rejecting the request. An analogy to this would be a defense lawyer

pleading a case to the judge without knowing any of the details of the charges against his client by the prosecution.

Right now PRAT does not have to provide any rhyme or reason for the decisions they make which can have profound effects on an individual and their family. Please add language to this bill that will require PRAT to explain what factors were considered and how and why they arrived at their decision in plain English.

Respectfully submitted: Stanley Peters

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Good morning members of the Public Health Committee. My name is the Reverend Kathleen Peters and I am a resident of Killingworth CT. (65 Parker Hill Rd. 860-663-1448, revkathyp@comcast.net) I have come to speak about Raised S.B. No. 294 AN ACT CONCERNING SERVICES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY. In the previous testimony my husband Stanley has laid out the concerns that we have with some of the wording in the bill and I want to add here my own personal words.

I have come before you a number of times over the past few years to fight for appropriate funding and treatment for my daughter Sarah and my cousin Carol both of whom live with intellectual disabilities. This bill, while it is not all that we might have hoped it would be, is a step to creating a DDS Family's Rights Bill. Life with a disabled person has many joy filled and rewarding moments but the challenges are great. Dealing with the DDS system should not be one of those challenges. While there are many capable and caring folks in the system the bureaucratic system itself is broken and dealing with it is often a nightmare. The system is set up so that it is often families against the system rather than families being assisted by the system. This bill will be a beginning to at least having families and DDS on the same page and talking the same language in regards to information and services provided.

We as families with loved ones with I/DD must deal with the DDS system, the DSS system, Social Security, probate courts and sometimes other governmental agencies in addition to whatever services providers are involved. I will tell you that I personally have two master's degrees and still keeping it all straight is often overwhelming for me.

Please support this bill with the corrections outlined above. Our children and our families need you to act.

Respectfully submitted The Reverend Kathleen Peters